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The adaptive role of perceived control before and after cancer diagnosis: A prospective study

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ABSTRACT

Cancer is generally considered a low-control situation. Stability of perceptions of control before and after cancer was examined, as well as the adaptive value of maintenance versus relinquishment of control in the psychological adjustment to cancer. This study, conducted in the northern Netherlands, was carried out in a prospective design with four assessment points (one pre-morbid and three post-morbid assessments) involving semi-structured interviews and self-report questionnaires. Ninety-nine newly diagnosed cancer patients all aged over 57 years completed all four assessment points. We found that perceptions of control declined before and after disease, possibly as a consequence of the diagnosis of cancer. Further, maintenance of control after cancer diagnosis was related to lower levels of psychological distress 6 and 12 months after diagnosis. These results suggest that maintenance of perceptions of control is beneficial to the psychological adjustment to cancer.

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Main text

Perceived control refers to beliefs that important aspects of one's life are under one's control. It can be considered as a learned expectation that outcomes depend on one's own choices and actions (Mirowsky & Ross, 1998; Rotter, 1966). The concept of perceived control in relation to adjustment to chronic illness has drawn considerable attention in recent years. There has been some debate with respect to the question whether perceived control is beneficial in all situations, or whether it is more adaptive in low-control situations to relinquish control. The hierarchical structure of beliefs people have about themselves and the world, as proposed by Janoff-Bulman (1989), is useful to answer this question. She argues that maintaining illusions at the level of basic human assumptions is adaptive, but that lower order beliefs dealing with more specific domains and interactions should match reality. Applied to the concept of control, this indicates that control over life in general should be adaptive regardless of the controllability of the situation, while specific control perceptions might be

maladaptive in some situations. Indeed, examining the literature on perceived control from this perspective shows that a disadvantageous effect of personal control was mostly reported when control with respect to specific aspects of the disease were examined, such as the course, symptoms or the cure of the disease (Affleck, Tennen, Pfeiffer, & Fifield, 1987; Christensen, Turner, & Smith, 1991). On the other hand, when general perceptions of control were examined, there is overwhelming evidence that control beliefs are beneficial when coping with different diseases, including cancer (e.g., Barèz, Blasco, Fernando-Castro, & Viladrich, 2007, 2009; Bremer, Moore, Bourbon, Hess, & Bremer, 1997; Henselmans et al., 2009a; Tennen & Affleck, 2000); and even may have stress-buffering potential (Helgeson, 1992, 1999; Henselmans, Sanderman, Baas, Smink, & Ranchor, 2009b; Penninx et al., 1996).

However, most studies assessed the adaptive value of general perceptions of control for adjustment to disease using a post-morbid assessment. While their findings do show that, once people are confronted with disease, general perceptions of control once are beneficial, they do not answer the question whether maintenance versus relinquishment of control is more beneficial for adjustment. Moreover, it is not clear whether pre- to post-morbid changes in perceived control occur at all. Therefore, in the present prospective study we will examine the role of general perceptions of control

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and changes therein in the adjustment to cancer. Adjustment to cancer is conceptualized as the course of psychological distress after diagnosis compared to distress before diagnosis. We address two issues: (1) the stability of perceived control before and after the diagnosis of cancer and (2) the relation between pre- to post-morbid changes in control and the course of psychological distress up to one year after cancer diagnosis, taking into account the pre-morbid level of cancer.

The diagnosis of cancer can be considered as a low-control situation (Thompson, Sobolew-Shubin, Galbraith, Schwankovsky, & Cruzen, 1993). Cancer is a serious life-threatening disease, and its diagnosis is likely to change patients' perceptions of control. Especially in the short term, cancer has its impact on the psychological well-being of patients, indicating the threat implied by cancer. Although there have been inconsistent findings, studies have shown that newly diagnosed patients initially react with an increase in psychological distress during the first year after diagnosis, indicating the stressful nature of cancer (e.g., Epping-Jordan, Compas, & Osowiecki, 1999; Hinnen et al., 2008; Rodrigue, Behen, & Tumlin, 1994; Schroevers, Ranchor, & Sanderman, 2006). And although the prognosis of the cancer may vary across patients, and consequently, the diagnosis of cancer need not be considered a low-control situation for patients with a good prognosis, the life-threatening nature of the disease, the extensive treatment modalities with uncertain outcomes, and the intrusiveness of the disease may challenge one's control perceptions, even in patients with a good prognosis. In general, there is little that patients can do to influence the medical course of the disease.

As defined before, perceived control can be considered as a learned expectation. Positive outcomes reinforce the sense of control, whereas negative outcomes can have a weakening effect (Mirowsky & Ross, 1998). In addition, McLeod (2003) has argued that control perceptions are established in a social context, in interactions with others. As such, perceived control is not a stable, trait-like characteristic; instead, it is susceptible to change. Indeed, several studies have shown that control declines with older age (e.g., Bailis & Chipperfield, 2002; Chipperfield, Campbell, & Perry, 2004; Kempen et al., 2005; Wolinsky & Stump, 1996), possibly as a result of an increasing number of confrontations with uncontrollable situations, such as death of significant others and own and other's diseases. Furthermore, the finding that perceptions of control vary with educational level, with higher educated having stronger perceptions of control (Bailis, Segall, Mahon, Chipperfield, & Dunn, 2001; Mirowsky & Ross, 1998), also indicates the role of environmental factors in the establishment of perceptions of control. These findings together suggest that perceptions of control are changeable due to environmental factors.

On the other hand, there are indications that people are able to maintain a sense of control, even in the face of uncontrollable situations. To understand this phenomenon, the two-process model of perceived control (Rothbaum, Weisz, & Snyder, 1982) is useful. This model distinguishes between primary and secondary control. Primary control refers to actual efforts people undertake to maintain and exert control, while secondary control refers to cognitive mechanisms individuals apply in order to maintain and exert control. This model assumes that the desire of primary control is a basic human need, and that when opportunities to engage in primary control efforts are diminishing, people resort to secondary control strategies in order to maintain a sense of control, which ultimately promotes better adjustment (Heckhausen & Schulz, 1995; Morling & Evered, 2006; Rothbaum et al., 1982; Thompson, Nanni, & Levine, 1994; Thompson et al., 1993). These mechanisms include illusory beliefs of control, downgrading one's expectations, and application of compensation mechanisms by redirecting one's control efforts to other domains than the one that has become less

controllable. Thus, applying these cognitive mechanisms may result in continued high levels of general control perceptions in a low-control situation like cancer.

Results with respect to changes of control in relation to cancer are scarce and mixed. A qualitative study of McVey, Madill, and Fielding (2001) has shown that lowered level of control was the most commonly reported issue by breast cancer patients before and after surgery. Quantitative studies corroborate this finding, by reporting lower levels of control among cancer patients who were assessed at various points after diagnosis (Ormel et al., 1997; Penninx et al., 1996) compared to non-patients. On the other hand, in line with Taylor's cognitive adaptation theory, in which illusory maintenance of beliefs is described, Stiegelis et al. (2003) have found that cancer patients showed greater comparative perceived control after radiotherapy than a reference group of cancer-free individuals. In other chronic diseases, Helgeson (1992) and Taylor (1983) have suggested that disconfirmation of control in case of chronic illness is only temporary; regaining a sense of control is part of the adjustment to illness. This was confirmed in a study of Henselmans et al. (2009b), where a temporary decrease in control was found among breast cancer patients. This pattern was observed only in women receiving chemotherapy; in other patients perceived control was stable. To conclude, the evidence regarding the stability of perceived control in the face of cancer or other chronic illnesses is equivocal.

Studies examining the adaptive value of maintenance of control are also scarce, because pre-morbid data are virtually lacking. Hence, we do not know to what extent people with low control after disease had higher levels of control before disease and how relinquishing control affects adjustment to cancer or other diseases. Some evidence is found in qualitative studies of Lowery, Jacobsen, and DuCette (1993) and McVey et al. (2001) showing that self-reported loss of general control perceptions after breast cancer diagnosis and stoma surgery, respectively, were related to poor psychological adjustment, indicated by levels of depression and anxiety. Furthermore, evidence for a health protective role of maintenance of control was provided in a longitudinal study among elderly, in which maintenance of control was related to a variety of health outcomes including functional status and overall health. Although this study did not concern psychological adjustment, the findings do suggest an adaptive role of maintenance of control.

To examine stability of control and its adaptive value, a prospective design is needed. In the present study, such a design was applied in order to examine the adaptive role of general perceptions of control before and after disease onset in newly diagnosed cancer patients. First, the course of control perceptions before and during one year after diagnosis is described, and compared to the level in a non-patient sample. Although results in the literature are mixed, we expected that patients would react to the diagnosis of cancer with a decline in control compared to the period before because we consider cancer as a low-control situation. However, we do expect individual differences, i.e., differences in the extent to which patients show a decrease in control. Second, the issue of maintenance of control versus relinquishment of control was addressed by relating change scores in perceived control before and after disease to psychological functioning in the mid- and long-term. Based on the literature, we expected that patients who were able to maintain a sense of control would show poor psychological functioning. In addition, we tested whether the relation between changes in perceived control and psychological adjustment is dependent upon prognosis. Following Christensen et al. (1991), who used disease severity as a proxy for objective controllability of the disease, prognosis of the disease was considered as an indication of the objective opportunities to exert control. A favourable prognosis would indicate that the diagnosis of cancer is not an objectively low-control situation per se.

Method

The present study is part of the Groningen Longitudinal Aging Study (GLAS). GLAS is a population-based prospective follow-up study of the determinants of health-related quality of life of older people, in particular, physical and social disability and well-being (Arnold et al., 2004; Kempen, Jelicic, & Ormel, 1997). The study started with a baseline assessment in 1993 and was conducted in the three northern provinces of the Netherlands, and ethics approval was given by University Medical Centre Groningen. A baseline assessment was conducted in a sample of 5279 persons of 57 years and older. The present study used a nested prospective cohort design of participants who experienced cancer in the five years post baseline and who consented to take part in a follow-up study were they to be diagnosed with cancer.

Sample

Cancer patients

People in the baseline sample who had given informed consent to provide medical data to the research team were monitored for cancer episodes by their general practitioner (GP). All types of cancer were monitored, with the exception of skin cancer. Four weeks after diagnosis, patients received a letter from the research team asking them to participate in the follow-up study, covering three follow-up assessments at 2, 6 and 12 months after registration of the disease episode. All eligible patients were approached, regardless of prognosis.

From baseline onwards, over a period of four years, 332 new cancer episodes were registered by the GPs. The period between baseline assessment and diagnosis was variable, ranging from 1 to 60 months ($M = 29.42$; $SD = 15.28$). Additional information could be collected from medical specialists, GPs and registration of the Comprehensive Cancer Centre North Netherlands (CCC-NN), which comprehensively records cancer incidence in Netherlands. These data confirmed the diagnosis of 216 cases and disconfirmed the diagnosis of 39 cases (benign or other diagnosis), while the diagnosis of 77 cases remained unclear. It was decided to include these 77 cases in the study because the disconfirmation ratio was 15% (39 disconfirmed cases/255 cases from whom medical data were available). Therefore, the loss of the validly diagnosed patients was considered much more harmful for the results than the inclusion of some invalidly diagnosed patients. Thus, 293 cases remained in the study. Of these remaining 293 cases, 15 had reported at baseline cancer in the six years prior to the current diagnosis. These patients were excluded because the prevalence of cancer would interfere with the analyses. Hence, 278 patients were eligible for the present study. Of these, 158 participated at T1; another 9 entered the follow-up study at a later assessment point (total $N = 167$; response rate = 60%). Of the 111 non-participating patients, 23 died before entering the study while the remaining 88 patients were excluded from the study because of study procedures ($N = 39$) or because they refused participation in further assessments during the study course ($N = 49$; see also Ranchor et al. (2002) for more details). When participants and non-participants were compared on relevant baseline variables, the only significant difference between participants and non-participants was found in pre-morbid level of perceived control (see next section for the description of the scale), with the non-participants ($M = 23.48$, $SD = 5.14$) having lower levels of perceived control than the participants ($M = 25.29$, $SD = 5.32$; $t = -2.54$, $p < 0.05$). The data presented here concern 99 patients (60% of all participants) who participated at all follow-up assessments. Reasons for T1–T3 dropout were mainly death and poor health. The dropouts were significantly older ($t = 3.66$, $p < 0.001$)

and included more lung cancer patients ($\chi^2 = 13.92$, $p < 0.05$). No differences were found in pre-morbid level of perceived control.

Data collection and procedures

Data were collected through semi-structured interviews conducted at the patients' homes and self-report questionnaires. During the interview, we collected sociodemographic data (age, gender, educational level). Data on perceived control and psychological distress were collected with self-report questionnaires. Data on disease stage were retrieved through the Comprehensive Cancer Centre North Netherlands (CCC-NN). Patients were not paid for their participation in the study but did receive a small present at each assessment point.

Perceived control

Perceived control was measured using the Mastery Scale (Pearlin & Schooler, 1978), translated by the members of the research team of GLAS (Kempen et al., 1997), which measures the person's sense of control over life in general. The Mastery Scale is often used in the context of chronic illness as a predictor of adjustment. The scale consists of seven items. A sum index was constructed ranging from 7 (low perceived control) to 35 (high perceived control). Cronbach's alpha of the scale was 0.79. Perceived control was assessed at all four assessment points. In the analyses, pre-morbid (T0) levels of perceived control as well as change scores in perceived control were used as predictors of psychological adjustment. Change scores from baseline (T0) to T1 were computed by subtracting the T0-scores from T1-scores; a positive value is indicative of a gain in control, while a negative value is indicative of a loss of control.

Psychological distress

We used the concept of general feelings of psychological distress to assess the outcome of psychological adjustment. The 12-item version of the *General Health Questionnaire (GHQ)* (Goldberg & Williams, 1988; Koeter & Ormel, 1991) was used to assess levels of psychological distress. The sumscore gives an indication of the severity of psychopathology: the higher the score, the more psychological distress experienced. Scores ranged from 0 to 36. Cronbach's alpha of the scale was high ($\alpha = 0.89$). The GHQ was assessed at all four measurement points.

Prognosis

For each cancer site in the study, disease stage was converted into a prognosis score, which covered three categories: poor, moderate or good. Doing so, an index for disease severity could be constructed across cancer sites. The data were collected from Comprehensive Cancer Centre North Netherlands. Not all patients gave informed consent for collecting medical data, but the data were available for a subset of the present sample ($N = 84$).

Statistical analyses

Differences between the baseline and follow-up assessments of perceived control among patients were compared to the baseline levels of non-patients with one-way ANCOVA, adjusting for age, gender and educational level. General Linear Model with repeated measures ANCOVA was used to examine changes in perceived control and psychological distress over time and the moderating role of prognosis herein. Effect sizes (Cohen's d) were computed as an indication of the magnitude of the changes. Pearson correlation coefficients were computed to assess the interrelations between the variables under study. Hierarchical regression analysis was performed to examine the relation between changes in perceived

control and changes in quality of life variables. In order to test whether the relation between changes in perceived control and psychological distress was dependent upon the severity of disease, these multiple regression analyses were repeated with prognosis and the interaction term of centred scores of perceived control and prognosis as additional independent variables.

Results

Sample

The sample consisted of 99 patients (57.6% male and 42.4% female) who could be included in the study at all assessment points. The average age was 71.8 years ($SD = 6.5$). Seventy-four percent of the patients had a partner, and the following cancer sites were found in this group: lung (8.1%), breast (16.2%), prostate (14.1%), gastro-intestinal (31.1%) urinary (16.1%), other (14.1%). The distribution of patients over four educational categories was as follows: I = elementary schooling (27.3%); II = lower vocational training (25.3%); III = secondary schooling/intermediate vocational training (32.2%); IV = higher vocational training/university (15.2%).

The course of distress

Before answering our main research questions, we first examined changes in psychological distress in the patient sample (see Table 1). The means and standard deviations of psychological distress (GHQ) indicated a significant change over time ($F = 9.50$, $p < 0.001$). Post-hoc analyses revealed significant increases in distress from T0 to all post-diagnosis assessment points ($p < 0.05$). In terms of effect sizes, the change between T0 and T1 was modest while the changes between T0 on the one hand and T2 and T3 on the other were small. There was a significant decrease in levels of psychological distress from T1 to T2 and T3, while the change between T2 and T3 was not significant. The results suggest that at group level, there was a lasting but small increase in the level of psychological distress after diagnosis compared to baseline levels, although there was a decrease after the first period after diagnosis (T1). The moderately strong correlation coefficients furthermore indicate individual variability in changes in distress before and after cancer diagnosis.

Changes in perceived control

In Table 1, mean perceived control scores of the patient group on all four assessment points are shown as well as the mean score in the baseline sample. First, we looked at changes over time within the patient sample. Perceptions of control changed significantly

over time ($F = 33.25$, $p < 0.0001$). Post-hoc analyses and effect sizes indicated a medium-sized decrease in perceived control level from T0 to T1, which continued until T2, resulting in a large difference compared to T0. From T2 to T3 perceptions of control increased significantly, although the change from T0 to T3 was still significant and medium-sized. Thus, compared to the baseline level, perceived control scores of the group decreased at follow-up. The sizes of the correlation coefficients, which were only moderately strong, suggest that changes also took place at the individual level. Further examination of individual changes revealed that only four patients (4%) showed a meaningful increase ($SD > 0.5$) in perceptions of control after diagnosis. Other patients either showed stable levels of control (48%) or a decrease in control (48%).

Because the decreased perceived control levels in the patient group could be due to the aging process, the levels of perceived control of the patient sample at the various assessment points were tested against the baseline level of people without cancer in the original sample. People newly diagnosed with cancer ($N = 278$) and people who previously had had cancer ($N = 182$) were excluded. This resulted in a reference sample of $N = 4819$ people, with a mean age of 69.4 ($SD = 7.0$), of whom 56.8% were female. Apart from gender and educational level, the results were corrected for age at the time the particular assessment was analyzed. This means that at baseline, the results were adjusted for age at baseline assessment, whereas at follow-up, age at the time of the diagnosis was used to adjust. By doing so, we could correct for possible aging effects, which was needed given the four-year patient inclusion. Analysis of variance showed that patients and non-patients did not differ significantly at baseline, whereas during follow-up, the levels of perceived control in the patient group were significantly lower than in the baseline sample. At T1 and T3, the differences could be considered as small, whereas at T2, the difference was medium-sized.

Finally, to examine whether the time interval influenced the changes in control, we tested whether there were different mean change scores between these groups: patients for whom the period between T0 and diagnosis was shorter than a year, those who had a time period between 1 and 3 years and those with a time interval longer than three years. There were no significant differences between these groups in mean change score, indicating that the magnitude of change was not dependent upon the time between T0 and diagnosis.

Although these results cannot be considered as a firm test of changes in perceived control as a consequence of the diagnosis of cancer, they do suggest that the levels of perceived control in the patient group decreased, probably as a consequence of the diagnosis. Therefore, we decided to use the change scores as an indication of loss of control.

Table 1

Mean scores (SD) of perceived control and psychological distress at baseline level (T0) for patients and non-patients and follow-up assessments for patients; statistics for between group comparisons adjusted for age at diagnosis, gender and educational level.

Variable	T0	T1	T2	T3
Perceived control				
Non-patients	24.69 (5.28)			
Patients	25.65 (5.27)	21.89 (4.19)	20.93 (4.19)	22.84 (4.48)
F	2.67	28.11***	50.37***	12.91***
Effect sizes between group comparison	0.18	0.42	0.56	0.27
Effect sizes within patient comparison (T1–T3 versus T0)		0.71	0.89	0.53
Pearson's correlation T1–T3 with T0 in patients		0.48***	0.44***	0.47***
Psychological distress				
Patients	9.55 (4.79)	12.80 (5.82)	10.90 (5.86)	10.92 (5.92)
Effect sizes within patient comparison (T1–T3 versus T0)		0.60	0.25	0.25
Pearson's correlation T1–T3 with T0		0.34***	0.31***	0.35***

Note: * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

Table 2Correlations between sociodemographic variables, perceived control T0–T3 and GHQ T0–T3 ($N = 86$).

	Control T0	Control T1	Control T2	Control T3	Control T0–T1	GHQ T0	GHQ T1	GHQ T2	GHQ T3
Age	–0.27**	–0.11	–0.23*	–0.15	0.21*	–0.13	–0.22*	–0.14	0.01
Sex	–0.11	–0.03	–0.13	–0.06	0.08	0.12	0.23*	0.13	0.19*
Education	0.29**	–0.10	0.01	0.00	–0.39***	–0.16	–0.18	–0.16	–0.21*
Control T0					–0.67***	–0.38***	–0.22*	–0.28*	–0.24**
Control T1					0.34**		–0.32**	–0.30**	–0.25*
Control T2					0.04			–0.26*	–0.18
Control T3					–0.08				–0.43***
Control T0–T1							–0.04	0.03	0.04
Prognosis	0.02	0.05	–0.10	–0.01	0.04	–0.12	–0.09	–0.08	0.04

Note: * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.*Interrelations between variables in the study*

Table 2 shows Pearson correlation coefficients of the interrelations between the variables in the study. More perceived control was moderately strongly associated with less psychological distress, with the cross-sectional correlations being the strongest. When the relation between prognosis on the one hand with psychological distress, perceived control scores and T0–T1 changes in perceived control on the other were computed for the subset of 84 patients, none of these turned out to be significant. The socio-demographic variables showed significant correlations with distress at T1 and T3. As to perceived control, older age showed less perceived control at T0 and T2, and with less change in perceived control. A higher educational level was moderately strongly associated with more pre-morbid perceived control, but not with post-morbid perceived control. In addition, a higher education was significantly associated with a larger decrease in perceived control.

Changes in perceived control in relation to adjustment

In Table 3, the change in perceived control scores for pre- to post-diagnosis were evaluated in relation to psychological distress 6 and 12 months after diagnosis. Besides the corrections for age, sex, educational level and pre-morbid GHQ, the results were also adjusted for pre-morbid perceived control. The reason for doing so was that changes in perceived control are dependent upon the actual perceived control level at T0. The beta-coefficients indicate that at T2 lower levels of pre-morbid perceived control and a greater reduction in perceived control were both predictive of distress. At T3, only the change score was significantly predictive of the level of distress. These results are different from the bivariate associations and can be ascribed to the entry of the baseline level of perceived control in the analysis. Apparently, reduction in perceived control in itself is not of significance for psychological adjustment but only in combination with the previous perceived control level. In order to test whether the time interval between baseline assessment and T1 affected the results, we repeated the

Table 3Standardized regression coefficients (β) for change scores in perceived control (T0–T1) with GHQ at T2 and T3 as the dependent variables, adjusted for age, sex, and educational level; changes in variance and cumulative variance explained.

	GHQ T2		GHQ T3	
	β	R^2 -change	β	R^2 -change
Age	–0.16		0.04	
Sex	0.04		0.07	
Educational level	–0.14	0.05	–0.18	0.05
GHQ T0	0.23**	0.08**	0.32**	0.10**
Control T0	–0.41**	0.03	–0.26	0.02
Control T0–T1	–0.34*	0.06*	–0.33*	0.06*
Cum. R^2	0.22		0.21	

Note: * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

analysis with entry of the time period between T0 and cancer diagnosis as an additional variable in the multiple regression analysis. Doing so did not change the results; the standardized regression coefficient for time period was only $\beta = 0.07$ (ns).

Entering prognosis in the analyses did not change the pattern of results. The regression coefficients of prognosis were $\beta = -0.04$ and $\beta = 0.04$ for distress at T2 and T3, respectively, whereas the aforementioned observations for pre-morbid control and the change score remained valid. The interaction term of prognosis and changes in perceived control was not significant.

Discussion

The aim of the present study was to examine the stability of perceived control before and after cancer and the adaptive value of changes in control for adjustment to cancer. The results indicate that individuals showed a decline in perceived control before and after diagnosis of cancer. Furthermore, this decline in control turned out to be maladaptive: those who were not able to maintain control after diagnosis were worse off 6 and 12 months after diagnosis in terms of psychological distress. These results were found irrespective of prognosis of the disease.

The finding that perceived control changed after the diagnosis of cancer is in line with our expectations. After diagnosis, there was a sharp decrease in level of perceived control. One year after diagnosis, patients seemed to recover with respect to their level of perceived control, although it was still lower than in a random sample of non-cancer patients of the same age and in comparison to their own level of perceived control before the diagnosis. In addition, the correlation coefficients suggest that there is individual variation in stability of perceived control. Changes in perceived control were largely independent of the prognosis of the disease, as was suggested by the low correlation between prognosis on the one hand and changes in perceived control on the other. The whole pattern of results, including the temporary decrease in control in the patient group and the comparison with the baseline sample, seem to suggest that the observed changes might be the results of the diagnosis of cancer. The lack of a control group as well as the variable time period between baseline assessment and T1-assessment do not permit firm conclusions, however. Changes in perceived control could be the result of other causes that are not known to us. However, assuming that the changes in perceived control are a result of the diagnosis of cancer, it remains unclear whether they are caused by the confrontation with an event over which no control could be exerted (i.e., the diagnosis of cancer), by the limited possibilities to exert control the consequences of the event (e.g., treatment choices, stressful medical procedures, lasting side effects including pain and fatigue, unattainability of important life goals) or by a lack of opportunities to control the course of the disease. These three different causes cannot be distinguished with our data set.

Furthermore, the results concerning decreases in perceived control as an independent predictor of adjustment during the first year after diagnosis suggest that maintenance of control is more beneficial than relinquishment of control, even in a low-control situation. The finding that the beneficial role of maintenance of perceived control was established independent of disease prognosis lend further support. However, the lack of moderation by prognosis might be because it is not an appropriate proxy for objective controllability. Prognosis captures only one specific aspect of the disease, i.e., its course, which is only one of the many aspects patients are confronted with when they receive the diagnosis of cancer. People might focus on a variety of other disease-related aspects rather than on their prognosis, consequently weakening its use as a proxy for objective controllability. Therefore, the findings with respect to the role of prognosis should be interpreted with caution.

In order to understand the beneficial role of maintenance of control before and after diagnosis in a low-control situation, the concept of secondary control is useful (Chipperfield et al., 2004). Maintenance of control might be the result of cognitive mechanisms people resort to, the so-called secondary control strategies. Several of these potentially adaptive cognitive mechanisms have been identified in the literature, including positive illusions and revaluing other aspects of life. Of these mechanisms, the adaptive value of positive illusions has been extensively studied in the literature. Laboratory studies have indicated that, in general, illusory control relates to better well-being (Thompson, 1999; Thompson, Armstrong, & Thomas, 1998). These findings pertain to the short term only, long-term findings are generally lacking. Additional support for the illusory mechanism was found in the work of researchers examining Taylor's (1983) cognitive adaptation theory (e.g., Stiegelis et al., 2003).

However, we cannot preclude the possibility that maintenance of control was the result of primary control efforts. As indicated previously, when people receive the diagnosis of cancer, they are confronted with a variety of disease-related aspects, some of which are still controllable. For example, patients may maintain control by actively exerting control through engagement in treatment choices. In a similar vein, people may exert control over other domains in life, for example, work or spare time, thus compensating for the loss of control they experience with respect to their disease. Loss of control over one aspect of the disease, for example, its prognosis, can also be compensated by exerting control over aspects related to the disease process. Thompson et al. (1993) have reported that compensation of loss of control in one domain was related to better adjustment to cancer, specifically when control was exerted over other aspects of the disease process. Henselmans et al. (2009a) found that engagement in social activities mediated the relation between perceived control as measured with the Mastery Scale and well-being. In addition, Carstensen, Hanson, and Freund (1995) showed a relation between perceived control and the application of compensation strategies. Thus, the benefits of control maintenance may be the result of active efforts to exert control, which in turn may result in better psychological functioning. It should be mentioned that although we discuss here behavioral compensation mechanisms, there are also cognitive compensation mechanisms, such as revaluing other domains in life, which could be considered as a type of secondary control.

In the present study, we have only evaluated the extent to which patients maintain control and not so much the mechanisms that are used to maintain control and that might explain its adaptive value. Future research should aim at disentangling the two types of control (primary and secondary) potentially involved in maintenance of control and examining the adaptive value of these two types of control. Identifying the specific mechanisms underlying

change or maintenance of control is of both theoretical and clinical relevance, especially when the adaptive value of these mechanisms is considered. In clinical practice, perceived control is an important variable in psychosocial interventions for cancer patients and other patient groups, implicitly or explicitly. The clinical implication of our findings is that it is important for patients to maintain or regain a sense of control, even in situations where there are few opportunities to exert control. In order to promote this, it is important to identify the mechanisms underlying maintenance of control.

The study has a few strengths and limitations that need to be acknowledged. The response data suggest a non-response rate of 40% when the sample in the present study is compared to the original eligible patient group. An explanation for this non-response rate is that, unlike other studies in this field, we were able to cover all incident cases in a selected sample, including those with a poor prognosis. It is likely that this produced the seemingly high non-response rates. Many longitudinal studies make restrictions with respect to the prognosis of patients by including only patients who are likely to survive during the study period. One reason for non-response was poor physical or psychological health. This brings us to another issue that needs further attention, i.e., the selective dropout in the study. As the data show, non-participants had lower levels of control compared to participants. There were no significant differences for level of distress, even if patients indicated that they did not participate because of poor psychological health. The fact that non-participants had lower levels of control might have affected our findings. People low on control are less likely to show changes in control. Therefore, the selective dropout might have resulted in a possible overestimation of changes in control in our study. Eventually, this may result in an overestimation of the relation between changes in control and course of distress. It is likely that maintenance of low control is related to high distress rather than to low distress, while in the present study we found that maintenance of control was related to low distress, perhaps because of the dropout of people low on control.

Furthermore, the validity of the pre-morbid assessment of perceived control may be questioned, given the variable time interval between pre-morbid assessment and diagnosis. Other events may have occurred, which may be responsible for the changes in control and distress. In addition, the magnitude of change in perceived control may vary with the time interval. Examination of these issues indicated that time between baseline assessment and cancer diagnosis did not change the present results. It was related neither to the magnitude of change nor to the course of distress. Therefore, the baseline assessment seems to be a valid pre-morbid assessment, despite the four years to diagnosis. Even then, the lack of a control group precludes causal inferences between cancer onset and changes in control. These changes might well be the result of natural ageing, as has been documented by Welch and West (1995), although we did find significant differences between control levels in the patients compared to the level in the baseline sample of elderly, and we did find an increase in the patient group between 6 and 12 months after diagnosis.

Despite these methodological limitations of the study, we believe that the present study, with its unique prospective design, adds valuable insights about the stability of perceived control and its relation to disease adjustment. This is important because the literature shows that as a group patients adapt fairly well, while at the same time there are individual differences in adjustment.

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